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Factors associated with perceived stigma of epilepsy in Croatia: A study using the revised Epilepsy Stigma Scale

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ABSTRACT

Purpose: It is believed that a large number of factors influence feelings of stigma, but their relative contribution is not yet entirely clear. Most studies to date were conducted using the Epilepsy Stigma Scale (ESS); only one used a revised version of the ESS (rESS). The following study aims to determine factors contributing to epilepsy stigma in outpatients with chronic epilepsy in Croatia, and to analyze some psychometric properties of the Croatian translation of the rESS.

Methods: Alongside standard testing for validity of the scale, a simulation model of the original ESS (smESS) was created. This model, which does not include a grading Likert 0–3 scale, was compared with the rESS.

Results: In total, 159 out of 298 subjects (53%) reported feeling stigmatised, with 136 (45%) mild to moderately and 23 (8%) highly. Internal consistency of the Croatian translation of the rESS was 0.887.

Feelings of stigma were significantly associated with age ≤50 years, younger age of epilepsy onset, more than 50 seizures to date, generalized tonic–clonic seizures, and a shorter seizure-free period. Multiple stepwise regression showed number of seizures to date as a significant variable (Beta = 0.246).

By adapting data into the smESS significant associations with younger age and age of epilepsy onset were lost. Internal consistency of the smESS was 0.849.

Conclusions: The Croatian translation of the rESS has been proved to be a suitable instrument for diagnosing epilepsy stigma. The results of our model point to the possibility that the rESS might be more sensitive than the original ESS.

1. Introduction

Epilepsy is a condition highly associated with feelings of stigma.[1,2] This is universally true among countries with different cultural backgrounds.[3–6] In Europe, the frequency of epilepsy patients experiencing stigma is reported as between 31% and 69%.[3,4,7–11] It is believed that a large number of factors influence feelings of stigma, ranging from social circumstances and seizure control to psychological traits of individuals with epilepsy. Some of the important factors seem to be number of seizures and seizure-free period, compliance with medication, age and age of epilepsy onset, employment status, level of family functioning, degree of self-esteem, and experience of anxiety and depression.[3,6,7,10–14] However, the relative contribution of these factors to stigma seems to vary across different European countries.[6,15]

Many studies addressing the contribution of different factors to stigma used the Epilepsy Stigma Scale (ESS), first described by Jacoby in 1992,[16] and later revised in order to detect more subtle differences in levels of felt stigma. So far, this revised stigma scale (rESS) has been used in only one study of subjects with recently diagnosed epilepsy,[11] as a subgroup of patients with epilepsy included in the SANAD trial.[17,18] In all other studies,[3,16,19–22] including the most recent one,[7,8] the original version of the scale was used.

Research on epilepsy stigma in Croatia has not yet been performed. Our initial hypothesis was that the prevalence of stigmatisation due to epilepsy would be similar to other European countries, but also that by utilizing the rESS, risk factors for stigma could be identified more precisely. Therefore, the aims of this study were to (1) determine factors contributing to feelings of stigma in

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outpatients with chronic epilepsy in Croatia and (2) analyze some psychometric properties of the Croatian translation of the rESS. Alongside standard testing for validity of the scale, a simulation model of the original Epilepsy Stigma Scale (smESS) was created. This model, which does not include a graded Likert 0–3 scale for each of the questions, was compared with the rESS. With this approach, we wanted to test the potential advantages of the rESS in epilepsy stigma research.

2. Methods

2.1. Subjects

Subjects were patients with epilepsy who attended regular visits as outpatients at one of the three participating hospital-based epilepsy services for adults in Croatia. Exclusion criteria were: inability to fill in the provided questionnaire without help, not taking AEDs and epilepsy that was diagnosed during the previous 6 months. The data were collected in each of the affiliations over 6 weeks, from the beginning of April until the end of May 2012.

3. Questionnaire

Subjects were asked to complete a questionnaire containing 9 questions concerning demographic data and clinical features of their epilepsy, and the revised version of the Epilepsy Stigma Scale (rESS), translated into Croatian. An official interpreter, together with the author of this study, has endorsed the Croatian translation. When completing the rESS, individuals are asked to respond on a scale of 0–3 (0 = not at all, 1 = yes, maybe, 2 = yes, probably, 3 = yes, definitely) whether, because of their epilepsy, they feel that other people are (1) uncomfortable with them, (2) treat them as inferior and (3) prefer to avoid them. In this way, a total score of 0–9 is obtained, where 0 represents no stigma, a score of 1–6 represents mild to moderate stigma, and a score of 7–9 represents high stigma.[11] Demographic data included age, sex, marital status, level of education and employment status. Clinical features included age of epilepsy onset, approximate number of all seizures, approximate number of 'major' seizures to date, and time period since the last seizure. In Croatian colloquial language, a generalized tonic–clonic seizure (GTCS) is better known as a 'major' seizure, so in the questionnaire we used this term instead of GTCS because we estimated that a proportion of subjects would not understand the clinical term. However, we report results pertaining to this question using the term GTCS. Number of seizures was a multiple-choice question with the following possible answers: *Less than 5*, *5–10*, *10–50*, *50–100* and *More than 100*, while the question about major seizures had the additional choice – *None*. Age of epilepsy onset and time period since the last seizure was free-response questions and these data were used to calculate duration of epilepsy (in years) and seizure-free time period (in days). When analysing education levels, subjects were divided into three categories: (1) elementary school, (2) secondary school and (3) college/school of higher education/university. When analysing employment status, subjects were divided into two categories: (1) unemployed/retired/disabled and (2) employed/in education.

4. Simulation model of the ESS (smESS)

In the original version of the ESS, individuals are asked to respond to the same three items, but instead of using a Likert scale 0–3, possible answers are dichotomous (either 'yes' or 'no'). In this way, the total score of the ESS is 0–3. We tried to make a simulation model of this version of the ESS based on the assumption that a subject who reported not feeling stigmatised when completing the rESS would choose the same answer when completing the ESS. Based on this assumption, using the answers obtained from the rESS, our smESS was calculated in the following way: if the answer was 0 (not at all), it remained 0, and if it was either 1, 2 or 3 (yes maybe, yes probably or yes definitely), it was scored as 1. In this way, the total score of the smESS was 0–3.

5. Statistics

For statistical analysis, IBM SPSS Statistics, Version 20.0 was used. Evaluation of the internal consistency of the scale was estimated by Cronbach's α test. Groups of subjects having no stigma, mild-to-moderate stigma and severe stigma were compared to find differences in clinical and demographic characteristics using analysis of variance and the χ^2 test, as appropriate. The analysis was performed separately using the smESS, and the results were compared with the ones using the rESS. For the multiple regression analysis, a stepwise model was used to determine the most significant variables among independent variables that were expected to have an influence on the total stigma scale score: age, age of epilepsy onset, duration of epilepsy and seizure-free period as continuous variables; sex, marital status and employment status as dichotomous variables and level of education, number of seizures and number of 'major' seizures as ordinal variables. Values of $p < 0.05$ were considered significant.

6. Results

Questionnaires were obtained from 310 subjects. None of the subjects who were asked to fill in the questionnaire refused to do so, but 12 (4%) failed to respond to at least one of the items on the stigma scale, so analysis was done on 298 subjects. Some of the respondents also failed to adequately answer one or more of the remaining questions, with the question about time since last seizure producing the most frequently missing or inadequate answers (32/298). These data, along with demographic and clinical characteristics, are shown in Table 1.

Internal consistency of the rESS was 0.887.

In total, 159 subjects (53%) reported feeling stigmatised, with 136 (45%) mild to moderately and 23 (8%) highly. Frequency of subjects feeling stigmatised did not differ significantly between the three outpatient centres (Centre No. 1: 51% of 76 subjects, Centre No. 2: 53% of 91 subjects, Centre No. 3: 54% of 131 subjects).

Feelings of stigma were associated with age $\leq$50 years ($\chi^2 = 6.435$, $df = 2$, $p = 0.040$), younger age of epilepsy onset ($F(2,289) = 4.635$, $p = 0.010$), more than 50 seizures to date ($\chi^2 = 11.536$, $df = 2$, $p = 0.003$), experiencing GTCS seizures ($\chi^2 = 7.085$, $df = 2$, $p = 0.029$) and a shorter seizure-free period ($F(2,264) = 3.420$, $p = 0.034$) (Table 2). No statistically significant association was found between stigma and sex, marital status, level of education, employment status or duration of epilepsy.

When multiple stepwise regression was performed, a significant model emerged ($F(1,237) = 15.329$, $p < 0.001$, adjusted $R^2 = 0.057$), with only one significant variable – number of seizures to date (Beta = 0.246), i.e. subjects who experienced more seizures had higher levels of stigma.

By adapting the obtained data into the smESS as described in Methods, associations of stigma score with more than 50 seizures to date ($\chi^2 = 8.784$, $df = 3$, $p = 0.032$), GTCS ($\chi^2 = 7.896$, $df = 3$, $p = 0.048$) and a shorter seizure-free period ($F(3,263) = 3.367$, $p = 0.019$) remained significant, while significant associations with age $\leq$50 years ($\chi^2 = 5.649$, $df = 3$, $p = 0.130$) and younger age of epilepsy onset ($F(3,288) = 1.538$, $p = 0.205$) were lost (Table 3). Internal consistency of the smESS was slightly lower than for the rESS, at 0.849.

Table 1
Baseline demographic and clinical characteristics.

N (number of subjects)	298
Age (years)	45 (16.3)[a]
Range	17–82
Sex	
Male	135 (45%)
Female	162 (55%)
Marital status	
Single	95 (32%)
Married/cohabiting	160 (54%)
Divorced	31 (11%)
Widowed	9 (3%)
Level of education	
Elementary School	51 (18%)
Secondary School	176 (60%)
College/School of higher education	20 (7%)
University	24 (8%)
Still in education	21 (7%)
Employment status	
Still in education	27 (9%)
Employed	79 (27%)
Unemployed (searching for work)	63 (22%)
Disabled	69 (24%)
Retired	53 (18%)
Age of epilepsy onset (years)	25 (17.8)[a]
Duration of epilepsy (years)	20 (14.8)[a]
Number of seizures to date	
Less than 5	89 (31%)
5–10	49 (17%)
10–50	53 (19%)
50–100	35 (12%)
More than 100	61 (21%)
Number of GTCS to date	
None	78 (27%)
Less than 5	94 (33%)
5–10	51 (18%)
10–50	26 (9%)
50–100	17 (6%)
More than 100	19 (7%)
Seizure-free time period	1079 (1743)[a]
≤6 months	120 (45%)
6–12 months[b]	28 (10%)
1–2 years[b]	32 (12%)
2–5 years[b]	37 (14%)
5–10 years[b]	32 (12%)
10 years or more	18 (7%)

Number of missing data: (age) 0, (sex) 1, (marital status) 3, (education) 6, (employment) 7, (age of epilepsy onset) 6, (number of seizures) 11, (number of "major" seizures) 13, (time since last seizure) 31.
[a] Results are shown as mean (standard deviation) days.
[b] Category defined as >lower limit and ≤upper limit.

7. Discussion

In most studies of epilepsy stigma, the original version of the ESS from 1992 was used,[3,7,8,16,19–22] while in our research we applied the rESS, as used in subjects from the SANAD trial.[17,18] These data regarding stigma of patients with new onset epilepsy from the SANAD trial were published in 2011.[11] In our research, the Croatian translation of the rESS proved to have good validity, with high internal reliability.

Our results have shown that in Croatia, the frequency of stigma among patients with epilepsy treated in hospital-based epilepsy services (53%) is similar to the frequency in some other European countries, although it is difficult to make a direct comparison due to the methodological differences in subject selection. In several large European studies, subjects were selected from support groups or from outpatient neurology clinics (stigma frequency 46%[15] and 51%,[6] respectively), and in a study sample similar to ours (a hospital-based epilepsy service) in Bulgaria, frequency of stigma was 43.62% and 4.7%, depending on whether the patients had pharmaco-refractory or pharmaco-sensitive epilepsy.[7] Furthermore, although the subject groups were considerably different regarding the duration of epilepsy, our figures were very similar to those of Taylor et al.,[11] where the frequency of stigma was 54% (47.3% mild-moderate stigma, 6.1% high stigma). Even though the possibility of direct comparison is limited, it seems that epilepsy stigma in Croatia is not considerably different than in some other European countries. This is in accordance with complementary studies that showed that public prejudices towards people with epilepsy in Croatia are generally not greater than in Western European countries.[23–28]

According to our research, several clinical and demographic factors are associated with stigma: younger age, earlier age of epilepsy onset, more than 50 seizures to date, experienced GTCSs and shorter seizure-free time period. Although the association of age with stigma did not prove significant using analysis of variance, when we divided the subjects into two groups with age of 50 years as a limit, as Taylor et al. did,[11] a statistically significant difference was obtained, with younger subjects expressing higher levels of stigma. Apart from chronological age, age at the onset of epilepsy also seems to be an important factor, as younger age of epilepsy onset was found to be a significant factor for stigma in several other studies.[6,15] Associations of stigma with seizure type and frequency have been reported previously.[6,11,14,15,19,21] Two studies also compared levels of stigma between subjects with and without a 6-month clinical remission[29] or a 2-year clinical remission,[19] and reported greater prevalence of stigma in subjects who were not in remission. However, to the best of our knowledge, this was the first stigma study where detailed data on time period since last seizure was obtained (subjects with more recent seizures usually responded in terms of days, weeks or months) and where this variable was significantly associated with stigma, i.e., subjects with greater degrees of stigma had progressively shorter seizure-free periods.

In an attempt to find the most important factor for stigma among the ones listed, multiple regression was performed. Our model, although statistically significant, accounts for only a small proportion of the variance of stigma score (adjusted $R^2 = 0.057$). The reason for this could be that we used a relatively small number of predictor variables, compared with other stigma studies with somewhat better predictive ability models.[6,11,16] Some of these studies reported that the contribution of clinical and demographic factors to stigma is relatively small compared with psychosocial variables.[14] Among the former, seizure frequency seems to be the most dominant,[14,15,19] which is in accordance with the most important factor found in our study – number of seizures experienced to date. The relative contribution of the most important factors for stigma also seems to vary between different European countries.[6,15] Results of our study, as well as those by others,[3,7,8,16,19–22] lead to the conclusion that stigma is a multifactorial condition with clear cross-cultural differences and that future studies should take into account the possibility of additional factors. Identifying and understanding these factors is crucial to intervention studies aimed at reducing stigma; if the factors that contribute to stigma are not identified they cannot be targeted.

Although further research leading to a better understanding of the factors contributing to stigma can be expected, the current insights can already have significant clinical implications. Being aware of these factors makes it possible to actively search for individuals who might be feeling a high level of stigmatisation, where the rESS or the ESS could have a leading role. After detection

Table 2
Relationship between stigma scale scores and demographic and clinical factors.

	rESS score			
	0	1–6	7–9	*p*-Value
Age (mean ± SD years)	46.97 ± 17.42	43.24 ± 15.79	40.17 ± 9.43	0.062[a]
Age (years)				
≤50	79	92	18	**0.040**[b]
>50	61	43	5	
Sex				
Male	63	57	15	0.123[b]
Female	76	78	8	
Marital status				
Married/cohabiting	83	68	9	0.076[b]
Not married	54	67	14	
Level of education				
Elementary school	24	24	3	0.362[b]
Secondary school	86	77	13	
College/university level	15	23	6	
Employment status				
Unemployed/retired/disabled	88	80	17	0.523[b]
Employed/in education	50	50	6	
Age of epilepsy onset (mean ±SD years)	27.35 ± 18.84	24.21 ± 17.09	15.36 ± 11.54	**0.010**[a]
Duration of epilepsy (mean ±SD years)	19.79 ± 15.67	19.28 ± 14.35	24.27 ± 11.69	0.341[a]
N of seizures to date				
<50	97	87	7	**0.003**[b]
>50	36	47	13	
N of GTCS seizures to date				
0	28	15	2	**0.029**[b]
1 or more	84	105	18	
Seizure-free time period (mean ± SD days)	1329 ± 1808	970 ± 1780	356 ± 538	**0.034**[a]

Bolded are values of $p<0.05$.
[a] Analysis of variance.
[b] χ^2 test.

of stigma, further individual analysis of stigmatising factors should be performed, as these are different in each person. Based on the results, a personalized therapeutic approach could be developed, including psychological, psychosocial and/or pharmacotherapeutic strategies.

Limitations of our study include not taking into account the possible influence of psychological factors and AEDs on felt stigma, as the independent contribution of these factors to stigma has been confirmed in previous research. Taylor et al.[11] found that PWE who reported experiencing higher levels of felt stigma were more likely to be classified as clinically anxious (62.5% vs. 17.3%) and depressed (47.9% vs. 6.6%). Also, a moderate correlation was found between depression and frequency and severity of stigmatization.[7] Associations of stigma with AEDs have been shown to be related to their side-effects[6] and the use of polytherapy.[7,14,15] It should also be acknowledged that this is

Table 3
Comparison of significant associations of demographic and clinical factors with stigma, using the rESS and smESS.

	rESS score				smESS score				
	0	1–6	7–9	*p*-Value	0	1	2	3	*p*-Value
Age									
≤50 years	79	92	18	**0.040**[a]	79	28	25	57	0.130[a]
>50 years	61	43	5		61	13	10	25	
Age of epilepsy onset									
Mean (years)	27.35	24.21	15.36	**0.010**[b]	27.35	22.39	24.17	16.48	0.205[b]
SD (years)	18.84	17.09	11.54		18.84	13.17	20.77	1.83	
N of seizures to date									
<50	97	87	7	**0.003**[a]	97	31	20	43	**0.032**[a]
>50	36	47	13		36	11	15	34	
N of GTCS seizures to date									
0	28	15	2	**0.029**[a]	28	6	4	7	**0.048**[a]
1 or more	84	105	18		84	29	29	65	
Seizure-free time period									
Mean (days)	1329	970	356	**0.034**[b]	1329	1386	406	839	**0.019**[b]
SD (days)	1808	1780	538		1808	2056	862	1674	

Bolded are values of $p<0.05$.
[a] χ^2 test.
[b] Analysis of variance.

the first study of epilepsy stigma in Croatia, with a relatively small sample size. Further studies should be performed before our data are generalized to all adult persons with epilepsy in Croatia.

Apart from the main aims of this study, we tried to make a contribution to the choice of scale – the original ESS or the revised version. So far, the ESS has been proved to be a suitable international instrument for diagnosing epilepsy stigma, and its conciseness makes it appropriate for everyday clinical practice. Although we are aware of the fact that a simulation model cannot replace true data acquisition and its analysis, the results of our model point to the possibility that the rESS might be more sensitive in the detection of factors contributing to stigma. In future, a larger study, preferably using both scales, is needed to verify this thesis, based on data presented in this paper.

Conflict of interest

None declare.

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